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## Advanced Care Planning at the End of Life for People with Dementia

### Conference or Workshop Item

#### How to cite:

Jones, Kerry and Richards, Naomi (2017). Advanced Care Planning at the End of Life for People with Dementia. In: Dementia and End of Life Care in Scotland, 13 Jun 2017, The Open University, Dumfries, Scotland.

For guidance on citations see [FAQs](#).

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[oro.open.ac.uk](http://oro.open.ac.uk)

- **90,000+ people with dementia in Scotland**
- **Progressive and life-limiting disease**
- **Complex physical and psychological needs**
- **Avoid unwelcome and distressing treatment**



# What is Advance Care Planning?

A ***process of discussion about end of life care*** involving the person with dementia, those closest to them, and their care worker, that usually takes place in anticipation of a future deterioration in the person's condition



**what you want to happen**

**what you *don't* want to happen**

# When Should Advance Care Planning be done?

**On admission to hospital**

**On admission to care home**

**At diagnosis**

**When you are ready**

# Who should be involved?

- **Person with dementia**
- **Family/ loved ones**
- **Healthcare professionals**
- **Dementia Practice Co-ordinator**





# What is covered?

## “My Anticipatory Care Plan”

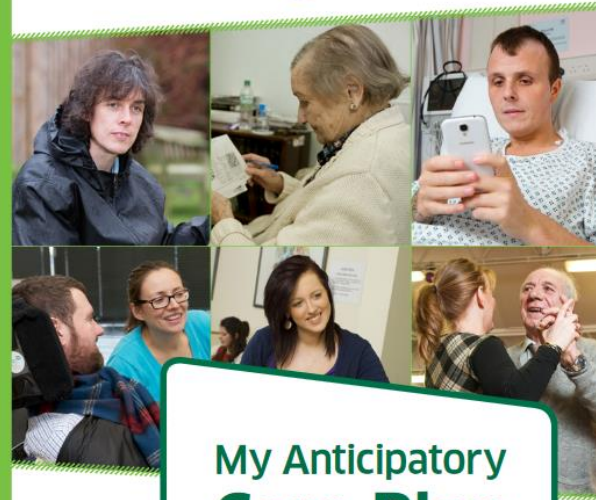
### Key Information Summary

#### Main Issues:

- Cardiopulmonary Resuscitation
- Difficulties eating and swallowing
- Antibiotics
- Pain
- Hospitalisation

Healthcare Improvement Scotland's Improvement Hub

➔ Let's think ahead



My Anticipatory  
**Care Plan**



## What does it avoid?

**Inappropriate hospital admissions  
(and associated costs)**

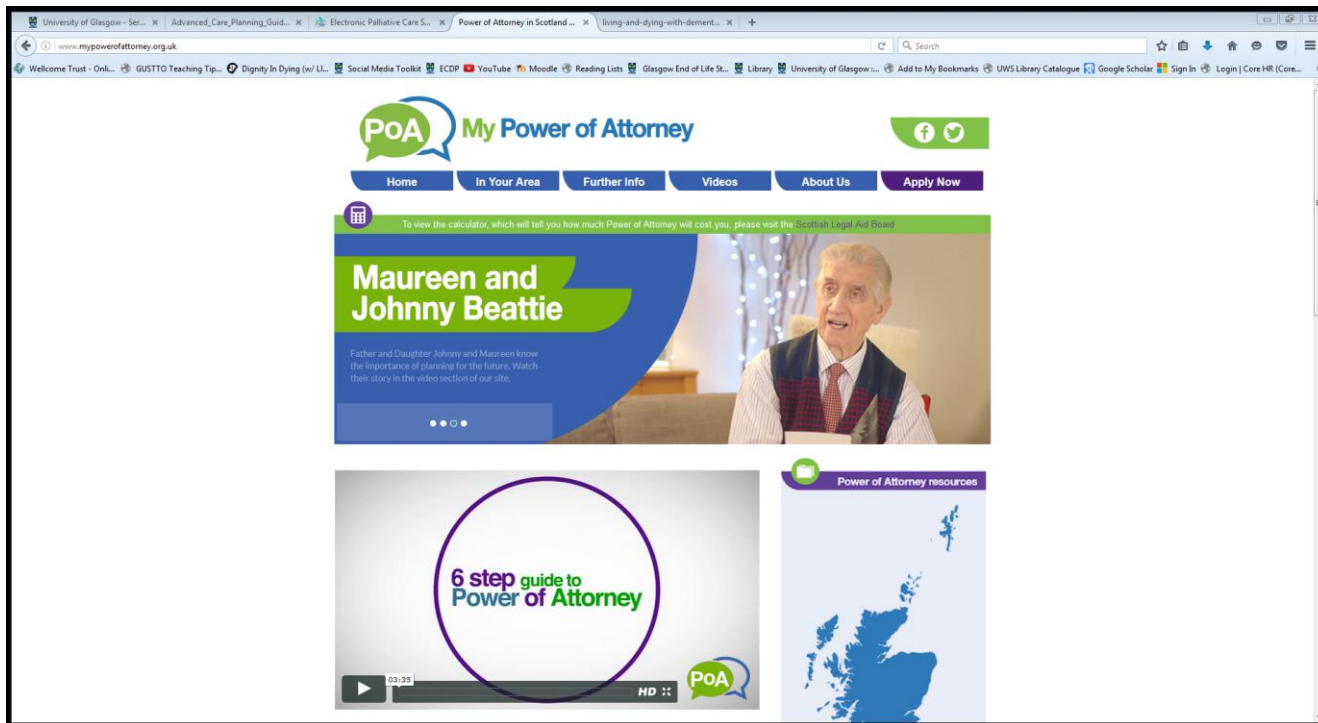
**Burdensome and futile treatment**

**Distress for families**





# Power of Attorney



The screenshot shows the homepage of the 'My Power of Attorney' website. The browser's address bar displays 'www.mypowerofattorney.org.uk'. The website features a green and blue color scheme. At the top, there is a navigation bar with links: Home, In Your Area, Further Info, Videos, About Us, and Apply Now. Below this, a banner for 'Maureen and Johnny Beattie' is visible, with the text 'Father and Daughter Johnny and Maureen know the importance of planning for the future. Watch their story in the video section of our site.' To the right of the banner is a video player showing an elderly man. Below the banner, there is a section titled '6 step guide to Power of Attorney' with a video player interface. On the right side, there is a map of the United Kingdom and a section titled 'Power of Attorney resources'.

University of Glasgow - Set... Advanced\_Care\_Planning\_Guid... Electronic Palliative Care S... Power of Attorney in Scotland ... living-and-dying-with-dement...  
www.mypowerofattorney.org.uk  
Welcome Trust - Onl... GUSTTO Teaching Tip... Dignity In Dying (w/ LL... Social Media Toolkit ECDP YouTube Moodle Reading Lists Glasgow End of Life St... Library University of Glasgow... Add to My Bookmarks UWS Library Catalogue Google Scholar Sign In Login | Core HR (Core...  
PoA My Power of Attorney  
Home In Your Area Further Info Videos About Us Apply Now  
To view the calculator, which will tell you how much Power of Attorney will cost you, please visit the Scottish Legal Aid Board  
Maureen and Johnny Beattie  
Father and Daughter Johnny and Maureen know the importance of planning for the future. Watch their story in the video section of our site.  
Power of Attorney resources  
6 step guide to Power of Attorney  
03:35 HD PoA

# Support for Family Members

- **More likely to have conversations when supported**
- **Need emotional support**
- **Need information on trajectory of dementia**
- **Need information on palliative and end of life care**

## The bottom line

**We need to provide a window of opportunity for people with dementia to make their wishes and preferences for the end of life known whilst they are still able to do so.**

**Not talking about it can have real consequences for the person with dementia, as well as for their friends and family and the professionals caring for them.**

# Government Action

The Knowledge Network You are not logged in. · Log In/Register · People Connect · Help and Training

## Living Well in Communities

NHS Education for Scotland

Resource Library Discussions Search

Home News Focus areas Events Blog Our team

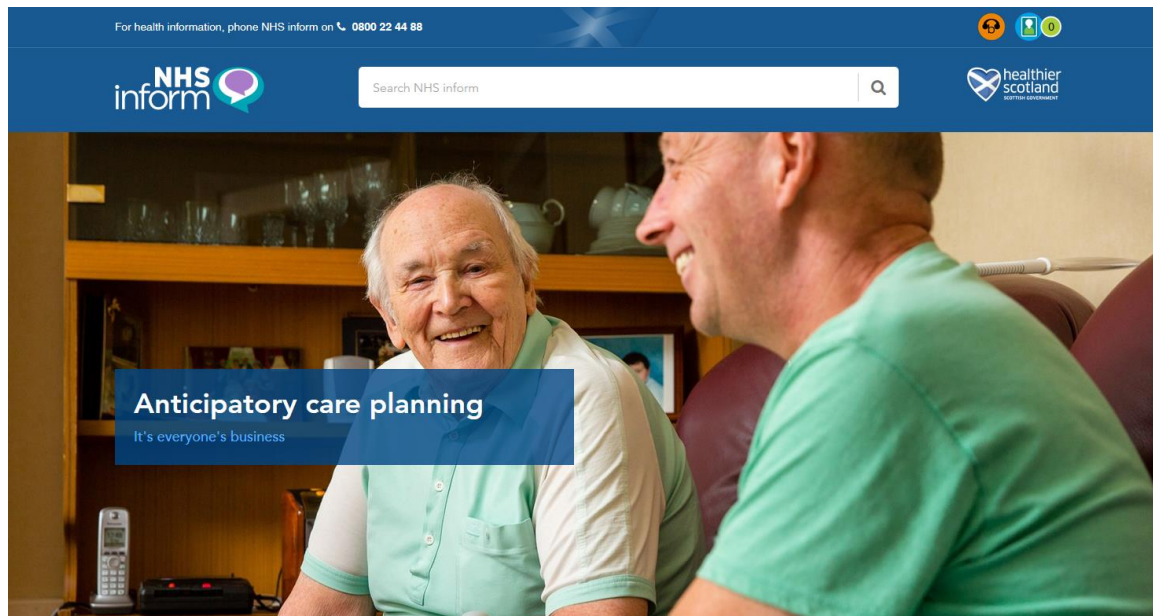
Home Focus areas Anticipatory Care Planning

### Anticipatory Care Planning



Anticipatory care planning involves discussing an individual's goals and wishes, and recording these decisions so that in the event of a gradual or sudden decline, those providing care have clear guidance on what that person would wish to happen.

# Resources to help you



# Resources to help you



The screenshot shows the ihub website, which is dedicated to supporting health and social care. The header features the ihub logo, a navigation menu with links to Home, About, Events, Latest News, and Contact, and a search bar. Below the header is a horizontal menu with six categories: System Enablers, Anticipatory & preventative care, Support in the community, Care away from home, Acute hospital care, and A-Z Programmes. The main content area is a collage of images showing diverse people in various settings. A prominent green banner in the lower-left corner of the collage reads "Anticipatory Care Planning Toolkit" and "Let's think ahead".

ihub  
supporting health  
and social care

Home About Events Latest News Contact

Search ihub Search

System Enablers Anticipatory & preventative care Support in the community Care away from home Acute hospital care A-Z Programmes

Anticipatory Care Planning Toolkit  
Let's think ahead



# Resources to help you



## Putting your house in order



#9  
Five things you can plan for end of life



## Time to talk?



#11  
Starting end of life care conversations with people affected by dementia



**There are things you want to raise, but it never seems the right time.**

Many of us who are getting on in years, or have an illness that we know will shorten our life, don't want to ignore the fact that our time is limited. There are things we want to get sorted out – like instructions for what we'd like to happen at and after our death.

We may want to talk to those close to us about our feelings for them, or what should be done if we become dependent, or what happens to those who are left behind. But these aren't easy subjects to raise – especially when those around us seem to want to ignore them.

To find out how to get more help visit:  
[www.goodlifedeathgrief.org.uk](http://www.goodlifedeathgrief.org.uk)  
or call 0131 229 0538

# Table Discussion

**What are *your* experiences of Advance/Anticipatory Care Planning?**



University  
of Glasgow



**INSPIRING  
PEOPLE**

[Naomi.Richards@glasgow.ac.uk](mailto:Naomi.Richards@glasgow.ac.uk)

[gla.ac.uk/endoflifestudies](https://gla.ac.uk/endoflifestudies)